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Amy Y. Kwan
The Effects of Oncology
Social Workers' Involvement
on Cancer Patients'
Decisions about End-of-Life
Care

ABSTRACT

The purpose of this study is to explore oncology social workers' level of involvement with cancer patients in a hospital setting and the effects this involvement might have on cancer patients' end-of-life care decisions.

Ten oncology social workers were recruited through a snowball sampling process. They completed demographic questionnaires and participated in semi-structured interviews. The narrative data was studied for prominent themes using thematic analysis. The findings underscored the importance of early social workers' involvement with cancer patients to provide guidance, support, and address emotional aspects of their cancer experiences. This study also notes that each cancer type follows a different disease and treatment courses that may influence when and how end-of-life issues are being handled. Although most patients seem to have an overall cognitive understanding of their medical conditions, the emotional integration and implications of this understanding might take time to process. Social workers' ability to facilitate communication among patients, families, and the medical team is one of their crucial roles in the interdisciplinary treatment team. Social workers' consistent support, hopeful approach and the on-going discussions with their patients promote understanding and readiness as patients' experiences with their illnesses evolves.

THE EFFECTS OF ONCOLOGY SOCIAL WORKERS' INVOLVEMENT ON
CANCER PATIENTS' DECISIONS ABOUT END-OF-LIFE CARE

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

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2009

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CHAPTER I

INTRODUCTION

Death is an integral part of life, but often people avoid acknowledging its existence until the very last moment. However, death is arguably one of the most powerful forms of transformation. If we are unable to acknowledge the presence of death, we could lose an experience rich with meanings, and our failure to acknowledge death may also affect the overall experience we have during our last days. Managing a terminal diagnosis can be difficult because the physical and emotional suffering that people in the dying process have to endure can be cruel and hard to accept. Individuals with life-limiting illnesses and their families need tremendous support to adjust to this major transition. End-of-life care is designed to address these very issues so that terminally ill patients will have an opportunity to continue to live meaningful and pain free lives in their last days.

The purpose of this study is to explore oncology social workers' level of involvement with cancer patients in a hospital setting and the effects this involvement might have on patients' end-of-life care decisions. The three sub-questions are 1) What types and extent of contact do oncology social workers have with their cancer patients who are receiving active care? 2) Do oncology social workers help clarify medical information such as diagnoses, prognoses, and treatment options, and implications on

quality of life with cancer patients and their families? 3) Do oncology social workers initiate discussions about death and dying with cancer patients and their families?

The rationale for this study is that although a significant number of physicians (Ogle, Mavis, & Wyatt, 2002; Sullivan et al., 2007) and oncology social workers reported strongly favoring the hospice philosophy, the referral rate to hospice care remains proportionally low, below 50 percent (Becker, 2004). Many health professionals recommended that patients utilize hospice for a minimum of three months in order to maximize the benefits from these services; however, those referred tended to use the care for shorter periods than recommended (McGorty & Bornstein, 2003; Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005; Teno et al., 2007). Furthermore, patients who are referred to hospice for less than a week are more likely to die in a hospital because hospice needs sufficient time to perform necessary assessments and to set up appropriate interventions to care for the patient at home (Teno et al., 2007).

Most hospice patients and families also reported benefits and favorable experience from utilizing the hospice services (Cherlin, Prigerson, Schulman-Green, Johnson-Hurzeler, & Bradley, 2005; McGorty & Bornstein, 2003; Rickerson et al., 2005; Weggel, 1999). It is important to explore the barriers that underlie the discrepancy between the physicians and oncology social workers' beliefs and the actual referral rate, as well as the discrepancy between patients and families' favorable experience and the relatively short use of services. Many factors go into the decision of switching treatment goals from life-sustaining measures to comfort measures. What might be more important is that patients and families have a clear understanding of their options so that patients' wishes may be appropriately addressed.

Hospice may not be the right option for all terminally ill patients, and there is not a prescribed length of stay that fits every patient's situation because the trajectories of illnesses near end-of-life vary widely with individuals (Levine & Karger, 2004). However, several studies concluded that the length of stay and the time of referral affect the perceived helpfulness of the services from bereaved family members (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005; Rickerson et al., 2005; Teno et al., 2007). Most patients and families believe patients had enrolled in hospice at the right time, but bereaved families are more likely to perceive hospice referral as initiated too late when the length of stay is shorter than 3 weeks (Kapo et al.). Longer hospice stays are associated with increased number of services and the perceived level of helpfulness of services by family members (Rickerson et al.; Teno et al.). Bereaved family members whose perception of being referred "too late," reported higher unmet needs, higher concerns, and lower satisfaction with the quality of end-of-life care (Teno et al.).

This qualitative descriptive study aims to create a portrayal of oncology social workers' experience that captures the nuances of their level of involvement with cancer patients. This study will then explore how these involvements might affect patients' end-of-life care decisions. The reason oncology is chosen as the focus of this study is because cancer has a more predictable disease trajectory, compared with other life-threatening illnesses, which is a main criterion for people to qualify for hospice care. The term "active care" is being conceptualized in this study as treatments that focus on curing and controlling disease, and the term "end-of-life care" is defined as treatments that focus on symptom management with an emphasis on comfort measures. Hospice care is a type of end-of life care that will be the focus of this study, and will be defined in the next section.

CHAPTER II

LITERATURE REVIEW

The purpose of this study was to explore oncology social workers' level of involvement with cancer patients in a hospital setting and the effects this involvement might have on patients' end-of-life care decisions. Thus, in this literature review, I will examine studies in the following areas: 1) Hospice care, 2) end-of-life prediction, 3) living with a life-threatening illness, 4) physicians' role in patients' end-of-life care choices, and 5) social workers' involvement in patients' end-of-life care choices. These sections will set the foundation for understanding barriers that have been identified to timely hospice referral.

Hospice Care

Hospice care in the United States is a somewhat newly established field. The first hospice in North America was opened in New Haven, Connecticut in 1974, and it was a borrowed idea that had been present in Ireland since the late 1800s and in England for many decades (Kastenbaum & Kastenbaum, 1989; Reese & Raymer, 2004). Hospice care is defined as a form of end-of-life care that can be provided in any setting (private homes, nursing homes, hospitals, hospice centers, or other long-term care facilities) for individuals facing life-limiting illnesses. Hospice focuses on symptoms management instead of cure or control of disease. Hospice is arguably a more appropriate and humane way of caring for individuals whose disease progression is no longer controllable. Using

an interdisciplinary approach, the primary goal of hospice is to relieve physical, psychosocial, and existential suffering. Hospice philosophy emphasizes the rights of patients to self-determination, and encourages the patients, families, and loved ones to participate in the caring process. Hospice care allows individuals with life-limiting illnesses to focus on the quality of living during the end of life (Silverman, 2004).

Hospice work was initially supported almost entirely by volunteer effort, donation, and grants. In 1983, Medicare began reimbursing for hospice services. Medicaid followed soon after in 1985. At that point, hospice emerged as a solid part of the healthcare payment system (Reese & Raymer, 2004). According to the National Hospice and Palliative Care Organization (NHPCO), there were an estimated 1.3 million people enrolled in hospice programs in 2006. Hospice cared for 36 percent of those who died in the United States. Although Medicare benefits were designed to provide end-of-life care to people who were expected to die within six months, in 2000, about one-third of those served by hospice died within a week of enrollment which indicates how underutilized these services are (National Association of Social Workers [NASW], 2002). In 2006, the national median length of stay in hospice was approximately three weeks (NHPCO).

End-of-Life Prediction

Choosing to accept hospice services is not a simple task. The actual progression from life to death is often ambiguous and unpredictable, but the Western medical model requires both physicians and patients to make major “life or death” decisions during this confusing and overwhelming time. In order to qualify the patient for Medicare hospice benefits, the physician needs to declare a clear prognosis that the patient has less than six

months to live. In order to be approved for hospice services, the patient needs to accept the terms to receive comfort care (for purpose of symptom management) and give up active treatment (for the purpose of curing or controlling the disease) (Casarett, Crowley, Steveson, Xie, & Teno, 2005; Friedman, Harwood, & Shields, 2002).

In recent years, medical advances that prolong the course of illness and treatment have created a new situation where the definition of *dying* has become blurry.

Physicians' prognoses shape the patients' understanding of their illness that affects their decisions about accessing end-of-life care. Bern-Klug (2004) suggested that our current conceptualization of *dying* has significant limitations. This contributes to the health care system providing inadequate end-of-life services and neglecting groups who might be at high risk of death due to extreme frailty or having multiple serious illnesses that could benefit from the services.

The predictability of the time frame during which someone might die varies widely by disease (Bern-Klug, 2004). For example, with cancer, which is the second leading cause of death, the process of dying is more predictable, more visible, and less ambiguous compared with heart diseases, the leading cause of death (Centers for Disease Control and Prevention [CDC], 2005). About 50% of all cancer patients will ultimately die from their disease (Linder, 2004). As a result, more cancer patients enroll in hospice programs compared to those with other illnesses (Casarett, Van Ness, O'Leary, Fried, 2006; Chen, Haley, Robinson, Schonwetter, 2003). According to *National Statistics on Death and Hospice* (1994) as cited by McGorty and Bornstein (2003), only about 42% of cancer deaths in the U.S. occur under hospice care.

With the proliferation of newer anticancer therapies, the prognosis for cancer patients becomes even more ambiguous. As described by Silverman (2004), the advent of new options comes with a set of new, unknown and complex consequences. Patients and families have to weigh various treatment options, anticipate and experience side effects, manage frequent fluctuations in functional ability and mood, and deal with the uncertainty of potential improvement or decline (Linder, 2004). New treatment options do not always equate to positive outcomes. According to Mintzer and Zagrabbe (2007), although many patients are on therapy trials for a significantly longer period of time, only a small percentage of patients respond to these therapies. For those who do respond, most of them only have a small extension of life expectancy. Physicians' prognoses shape the patients' understanding of their illnesses and affect their decisions about treatment options and end-of-life care. Faced with multiple complex decisions, patients and families must receive honest and realistic information about their prognoses, treatment options, and expected quality of life, in order to make informed decisions about their care.

Living With a Life-Threatening Illness

Individuals facing life-threatening illnesses such as cancer endure tremendous physical and psychosocial sufferings that affect their quality of life. Literature (Linder, 2004) has suggested that all patients and families could benefit from emotional support when faced with such medical trauma. When physical symptoms and other psychosocial issues are appropriately addressed, terminally ill patients showed a decrease in their desire to hasten death (Arnold, 2004; Schroepfer, 2007). Symptom management such as adequate palliative care and communication about end-of-life issues have been identified

by terminally ill patients and families as key elements to enhancing quality of care during end-of-life (Arnold; Heyland et al., 2006; Schroepfer; Sullivan, 2007). Initiating a caring line of communication helps address emotional distress and contributes to the dying patients' perception of being heard, making their condition more bearable (Schroepfer). Helpful ways that have been identified to enhance communication include offering sufficient informational and emotional support (Butow, Dowsett, Hagerty & Tattersall, 2002; Csikai, 2006; as cited by McGorty & Bornstein, 2003; Schroepfer); providing time and opportunity for patients and families to express their hopes, fears, and wishes (Butow et al.; Schroepfer); and including patients in the treatment planning and updating them about their conditions (Butow et al.; Cherlin et al., 2005; Schroepfer). Physicians who spoke with patients about the possibility of dying were more likely to report higher satisfaction with end-of-life care provided to patients (Sullivan et al., 2007).

Although anyone can refer patients to hospice at any point in time, many patients have limited support and resources and the physician might be their only consistent support and source of information. Furthermore, it is understandable for most patients and families to choose to explore end-of-life care options with someone whom they have an established relationship who has an understanding of their illnesses and circumstances. Both patients and families seem to agree on the importance of having a trusting relationship between physicians and patients and their families (Butow et al., 2002; Heyland et al., 2006). Long-term relationships help build trust and allow physicians to better understand patients' situations, support them, and help physicians to better facilitate difficult conversations (Butow et al.).

It is important to respect patients' decision to refuse information to the same degree as their decision to be kept fully informed (Ziberfein & Hurwitz, 2004). While not all patients may want to know that death is imminent, studies show that the majority of patients would like an opportunity to discuss this "unavoidable possibility" (Sullivan et al., 2007). Physicians and other health providers should continuously assess patients' and families' readiness to receive information and be prepared to resume discussion when they become ready (Linder, 2004). Patients' and families' feelings about having end-of-life care discussions are likely to change overtime depending on patients' physical and psychosocial condition in relation to the dying trajectory (Linder, 2004; Ziberfein & Hurwitz).

Another reason this conversation should take place at an earlier time is because in a crisis situation such as receiving a poor prognosis, people might need to hear the same information repeatedly in order to understand or fully grasp the information (Csikai 2006; Linder, 2004; Ziberfein & Hurwitz, 2004). One reason could be that patients and families often feel overwhelmed by the vast amount of important information they have to master (Linder). It is also normal and expected for patients to engage in their defense mechanism and go through an initial period of disbelief, avoidance, or denial when they first learn about their life-limiting diagnosis (Clayton, Butow, Arnold, & Tattersall, 2005). Allowing people to feel and to express their intense feelings is a way to validate their experience and to begin to address some of the complex emotions that people might need to confront throughout the dying process (Linder; Ziberfein & Hurwitz). Taking time to get to know the patient and their family's psychosocial circumstances, coping

styles, and values and beliefs can help providers to better understand their difficulties and to offer appropriate support during this difficult time.

Physicians' Role in Patients' End-of-Life Care Choices

Physicians are usually the first people to bring up information about end-of-life care to patients and families (Chen et al., 2003; Csikai, 2006). Physicians are described as the gatekeepers to hospices because they are the ones who need certify that a patient has less than six months to live in order to qualify for Medicare hospice benefits (Cherlin et al., 2005; McGorty & Bornstein, 2003; Ogle et al., 2002; as cited by Weggel, 1999). Having a clear understanding of the prognosis is a necessary first step to helping patients and families explore possible treatment options (Butow et al., 2002; Casarett et al., 2005; Casarett et al., 2006; Clayton et al., 2005; Heyland et al., 2006; Weggel). Some patients have suggested that the term prognosis should include life expectancy information and its practical implication for their quality of life so that patients can have a better understanding of what to expect of the disease course and the possible implication it has for them and their families (Clayton et al.).

Although physicians are expected to provide diagnoses to patients, information about prognosis is less frequently presented even when the patient requests this information (Butow et al., 2002; McGorty & Bornstein, 2003; Sullivan et al., 2007). Cherlin et al. (2005) and McGorty and Bornstein found that physicians often do not inform patients about their incurable prognosis until very late in the course of their illnesses. Numerous studies have also explored physicians' difficulties with discussing poor prognosis and end-of-life options (Butow et al.; Cherlin et al.; Clayton et al., 2005; Friedman et al. 2002; McGorty and Bornstein; Ogle et al., 2002; Sullivan et al.).

Whether a physician decides to give a terminal prognosis is mainly determined by the degree of certainty that death will occur within a predictable timeframe. Most physicians are reluctant to give a terminal prognosis until they have high clinical confidence and do not discuss the option of end-of-life care until the very last moment (Cherlin et al.; Clayton et al.; McGorty & Bornstein; Weggel, 1999). Sullivan et al.'s (2007) secondary exploratory analysis of interviews with 196 physicians found that over the course of hospitalization, 86% of the physicians reported that they were aware that their patient would die; however, fewer than half of these patients were told this information. Most physicians reported that they did not feel certain about imminent death until days (57%) and hours (18%) before the patient died. Among patients with a medical team who were aware that death was imminent weeks (14%) before the patient died, 42.9% of these patients were never told. Unfortunately, the closer it gets to the time of death, the more likely patients may not be conscious or too frail to receive this information.

A number of studies have found that physicians have difficulty fully taking on this role of discussing end-of-life care on their own because of their own lack of knowledge about hospice and personal discomfort about discussing death (Cherlin et al., 2005; Desharnais, Carter, Hennessy, Kurent, & Carter, 2007; Friedman et al.; McGorty & Bornstein; Weggel, 1999). Another barrier that contributed to physicians' low incidence of hospice referral is that they are trained from a cure-oriented perspective and might have a strong bias toward curative care over comfort care (Friedman et al.). This can lead to physicians overestimating life expectancy, waiting until the patient has exhausted all options, or is too fragile to transfer. For these reasons, the discussion of end-of-life care

options with patients and families is often delayed and that important hospice care opportunities are missed.

Some physicians attempt to protect patients and families by keeping life-limiting diagnosis and poor prognosis information from them. Other well-intentioned physicians might feel that exploring options for end-of-life care may destroy patients' and families' sense of hope, and therefore decide that the discussion should be postponed until after all treatment possibilities have been exhausted (Ziberfein and Hurwitz, 2004).

Unfortunately, these well-intended behaviors end up creating false hope that prevents patients and families from deciding on appropriate care and making realistic plans for themselves and their loved ones. Patients who do not receive adequate prognostic implications of different treatment options are more likely to choose aggressive treatments that may not extend their life but may compromise their quality of life greatly (Butow et al., 2002; Clayton et al., 2005; Weeks et al., 1998).

The literature seems to indicate that many physicians lack the training, skills, and professional experience to recognize the need to transition patients from curative care to comfort care (Friedman et al., 2002; Last Acts, 2002). Other busy physicians who meet with their patients intermittently may easily overlook patients' change of health status and the need to transition to comfort care (Linder, 2004). Physicians also seem to lack concrete knowledge about hospice care that may influence their likelihood to explore this option with their patients. In Ogle et al.'s (2002) study, physicians rated "unsure" (64%-88%) for half of the survey questions regarding hospice knowledge on policies and services they offer. Yet only 45% of the physicians reported being uncertain about types of covered services and benefits as barriers to hospice referral. The underreporting could

reflect physicians' lack of awareness about the gap of knowledge that may affect their referring patterns and behaviors. Friedman et al. vividly described physicians' experience of coming to terms with a terminal diagnosis:

Coming to the realization that curative care can no longer benefit a patient brings the physician and the patient face-to-face with death, which is a discomfoting and awkward transition, and one that physicians often view as their own personal failure. In fact, many physicians lack the professional experience, skills, and training to recognize the need to move patients from curative to comfort care and help them make that move. (p. 74)

Interestingly, study data has showed that patients, families, and physicians all seem to express a desire for earlier hospice referral, but each attributed reasons for delay to others' unwillingness or lack of readiness (Csikai, 2006; Ogle et al., 2002; Weggel, 1999). An in-depth look with the purpose of understanding each group's perceptions about their personal difficulties with engaging in a end-of-life care discussion could unveil reasons behind the seemingly contradictory views.

Social Workers' Role in Patients' End-of-Life Care Choices

Most health professionals agree that the task of supporting the patient in coming to terms with the news of a poor prognosis need not be on physicians' shoulders alone (Butow et al. 2002). End-of-life care is not a new concept for social workers who have historically provided care for dying individuals and their families in various settings (National Association of Social Workers [NASW], 2004; Reese & Raymer, 2004). Csikai's (2006) study also found that social workers were most comfortable, knowledgeable, and available (setting) during the communication process with patients about end-of-life issues.

As mentioned earlier, patients may experience certain psychological barriers that interfere with their comprehension of poor prognosis, O'Donnell (2004) and Linder (2004) also suggested that the language used to present medical information may be so technological or complex that sometimes patients and families may not have a clear understanding of what was said to them. Some patients and families may avoid asking for clarification out of fear of appearing ignorant. An added difficulty for facing a serious or life-limiting diagnosis is that the emotional impact can impair concentration and logical thinking (Linder). Social workers' early intervention in improving communication patterns, providing support, and ensuring that patients and families understand the presented information can prevent miscommunication and facilitate the process of helping patients and families to make informed decisions (O'Donnell).

Even though most patients want to hear information relating to their diagnosis, treatment options, and prognosis from a physician, social workers can help physicians speak in terms that their patients can understand. Social workers can also redirect patients back to physicians to review critical information that might not be clear for patients or families (Zilberfein & Hurwitz, 2004). Social workers fill an important role as a liaison between patients and the medical team by promoting better understanding of all perspectives and by ensuring that true communication occurs (Fineberg, 2004; Linder, 2004; O'Donnell, 2004; Zilberfein & Hurwitz).

There seem to be many benefits to a social worker's early involvement with cancer patients. Reese and Raymer's (2004) study indicated that social workers' involvement has a positive correlation with the overall satisfaction of the patients and the hospice team functioning, as well as lowering hospice cost. The authors pointed out that

social workers' participation in the intake interview and continuing intervention is crucial in coordinating comprehensive quality care among the patient, family, and healthcare providers. By using an ecological perspective, social workers are skilled in identifying needs and problems early on to perform crisis prevention, and therefore reduce the severity of cases. The benefits of social workers' involvement should be transferable to the hospital setting. According to Linder (2004),

Early in the process, physicians and the interdisciplinary team can do much to promote better patient understanding of the evolution of their disease and the medical response to it. Such early efforts promote a stronger bond between patients, physicians, and the treatment team and can serve to establish the social worker as a valued resource for patients. (pp.696-697)

According to Levine and Karger (2004), the social worker has a unique perspective that can have a tremendous impact at every stage of illness (beginning stage, treatment stage, and terminal stage). While the physicians pay attention to the medical aspects of the patient's illness, social workers work on understanding and interpreting the emotional aspects of the treatment process and offer insight to the patient, the family, and the medical team. Social workers' active and collaborative early intervention with newly diagnosed patients can also help them to develop coping skills and strategies they can use during the predictable crises (i.e., adjustment to new diagnosis, starting treatment, waiting for test results, recurrences, complications, change in health status, exhaustion of all treatment option, and transition to comfort care) throughout their illnesses (Linder, 2004).

Through their clinical expertise, social workers can help normalize the living and dying process as a continuum of health, help patients to explore and understand their illnesses within contexts of their lives, offer opportunities for patients and families to process difficult emotions around various levels of losses, and explore treatment

decisions that address both patients and their families' needs. Social workers should also pay attention to the patient's evolving self-concept as the disease evolves. Patients' self-identity, role, and status are shaken by their cancer diagnoses and prognoses, and will remain so over the entire course of the disease (Levine & Karger, 2004; Linder, 2004). Unfortunately, untimely referral to social work may prevent patients and families from receiving support and caring communication that they desperately need. As described by Zilberfein and Hurwitz (2004),

The time of the initial diagnosis of life-limited illness is the optimal point to begin clinical work. In most cases, however, contact with a social worker begins either at the terminal diagnosis when the patient is referred to a hospice program, or during an acute episode or illness in a hospital when referral to palliative care is made. It is particularly difficult to begin to cultivate hope in patients at this advanced stage of their disease processes. (p. 314)

Even when social workers are able to engage their patients in a conversation about end-of-life issues, there are other factors that affect the accessibility and timeliness of hospice referrals. Part of the complication of working with terminally-ill patients is that many people are involved in this process and people often don't reach the same decision at the same time. There may be difficult time-sensitive treatment decisions to be made and people may or may not knowingly inject their personal views about what they consider a good death. Becker (2004) found that the majority of oncology social workers in his study reported having encountered resistance from many patients and their families to accepting hospice referrals. The refusal to accept hospice care and discontinue active treatment could be a reflection of the denial of the reality of the situation, lack of sufficient understanding of the prognosis, or the result of a desire to continue to try.

However, the author also mentioned that social workers' thoughts and feelings about hospice can influence whether or not their patients are referred for hospice services.

Similar to respecting a patient's decision to receive poor prognostic information, a patient's end-of-life care decision also needs to be respected. Zilberfein and Hurwitz (2004) pointed out that "It is important to make sure the family understands the choices at hand. Once this has been assured, however, the family's choices should be respected and supported" (p. 313). The social workers' role is not to ensure that patients fully accept and come to terms with their diagnoses in the face of clear medical evidence, but to create a safe space for patients to make sense of their situations and to essentially accompany them through the unfamiliar journey (Zilberfein & Hurwitz; Linder, 2004). According to O'Donnell (2004),

Social work is a values-based profession and is particularly suited to addressing value-laden decisions that patients and families face in modern health care. As patients and families struggle with understanding the parameters of care and accepting the limitations of interventions, social workers can help resolve these difficult issues and manage their consequences. (p.172)

It is important for social workers to be self aware of their own feelings and biases to prevent imposing their own beliefs onto their patients. Social workers' training, values, and professional standards make them an invaluable member of the treatment team to support both patients and staff through the emotional process of working with seriously ill patients. As Ziberfein and Hurwitz (2004) describe,

Social workers are trained to be self reflective, to have a high degree of self-awareness, and to provide crisis intervention with family members. Clinically trained social workers are aware of transference/countertransference phenomena, maintain strong boundaries, understand the patient and family from a biopsychosocial and cultural perspective, and perhaps most importantly, are skilled in the therapeutic use of self (p. 320).

To date, limited studies have explored oncology social workers' role in facilitating communication about medical information and end-of-life care with cancer patients and their families. By understanding oncology social workers' current role and clinical practice in working with cancer patients in a medical interdisciplinary team setting, we hope to gain insight about how social workers' involvement might affect cancer patients' end-of-life care discussion and decisions, and to develop best practices to address needs and improve continuity of care for individuals with serious and life-limiting illnesses. One clinical implication of the potential findings may be to encourage oncology social workers to play a more active role in providing information and facilitating discussions that may affect cancer patients and their families' ability to make informed treatment decisions. Policy implications may include requiring hospitals to ensure that all newly diagnosed cancer patients are referred to a social worker. Another implication may be to clarify roles among interdisciplinary team members to allow social workers to play a more active role with these patients. Implications such as these will be discussed further in the discussion chapter.

The following chapter outlines the descriptive methodology that will be used to investigate the topic areas of inquiry. It explains the choice of design, sampling, data collection, and data analysis.

CHAPTER III

METHODOLOGY

The purpose of this qualitative descriptive study was to understand social workers' involvement with cancer patients and the effects they have on cancer patients' end-of-life care decisions. The overarching research question is how does oncology social workers' involvement affect cancer patients' decisions about end-of-life care? The three sub-questions are 1) What types and extent of contact do oncology social workers have with their cancer patients who are receiving active care? 2) Do oncology social workers help clarify medical information such as diagnoses, prognoses, and treatment options, and implications on quality of life with cancer patients and their families? 3) Do oncology social workers initiate discussions about death and dying with cancer patients and their families?

A flexible qualitative descriptive design was chosen because the purpose of this study is to create a portrayal of oncology social workers' experience that captures the complexities of their clinical practice and their current role working with cancer patients and their families in a hospital setting. The purpose of a descriptive research is to develop a better understanding of the phenomenon in a particular point in time (Anastas, 1999). These rich descriptive data might generate themes that would be difficult to elicit otherwise. This type of research attempts to explore what a phenomenon looks like rather than how it works. The data collection method was comprised of structured open-

ended questions in an interview format to gather rich narrative data from the study participants.

Sample

The sample consisted of 10 English-speaking social workers with a Master in Social Work degree who have experience working as medical social workers in a hospital setting for at least two years and are currently employed as an oncology social worker at their current job for at least 12 months. The rationale for having the length of experience criteria was to rule out any adjustment issues of functioning in an unfamiliar role that may affect their behaviors.

Exclusion criteria included 1) Social workers who have not received a Master in Social Work degree; 2) Social workers who have less than two years of medical social work experience; 3) Social workers who have not worked at the present job in an oncology unit for the past 12 months; 4) Social workers who do not work in the greater Boston area; 5) Social workers who are non-English speaking (because there is no funding to hire interpreters for this study).

Research Method and Design

Data Collection Methods

After receiving a letter of approval (Appendix A) from the Smith College Human Subject Review Committee, I recruited 10 participants through snowball sampling, a form of non-probability sampling. I started by interviewing two seasoned oncology social workers who had agreed to share their personal perspective, independent of the hospital where they were currently employed, on their experience of working with individuals who have a cancer diagnosis. The rest of the sample was obtained by having

participants and other social workers to refer me to their colleagues who might be interested in participating in this study. These individuals then referred me to others and the process continued until I had obtained my sample of 10 participants. My referral sources provided me with potential participants' contact information and informed them that I would be contacting them. Due to resource limitations, all participants were recruited in the greater Boston area.

Once an interested social worker was identified, I contacted them by phone or email to explain the premise my study. I screened these referents to confirm their interest and to determine whether they meet the inclusion criteria. If they decided to participate, we scheduled an interview meeting at a quiet, public place upon which participants and I had mutually decided such as a library or participants' office. I then emailed them a copy of the informed consent letter (Appendix B) to review and for their record. This gave participants a chance to address any concerns they may have and have time to evaluate their readiness to participate.

This researcher conducted an interview with each participant for no longer than 60 minutes. I went over their rights as a participant and asked them to sign the informed consent letter prior to starting the interview. I emphasized that their participation was voluntary and informed them of their rights not to answer or to discontinue participation at any time without penalty. Participants then completed a short demographic questionnaire (Appendix C) to provide basic information such as age, gender, race/ethnicity, hospital unit they were working in, the number of years employed at the current hospital, and the number of years employed as a medical social worker. The questionnaire required no more than five minutes to complete. Next, this researcher went

through a list of guided interview questions (Appendix D) with the participants.

Interviews were audio recorded and transcribed in full by this researcher.

I chose interviews as the main research method because it can provide an in-depth description of the current phenomena and will reflect at length, the intricacies of complex feelings, understandings, and past experiences (Anastas, 1999, p. 351). The interview consisted of structured open-ended questions to allow participants to convey an in-depth and nuanced picture of their regular interaction with cancer patients and their families. At the same time, the structured questions offered a level of control and consistency with what and how the questions were being asked. Structured questions also allowed both researcher and participants to focus on specific aspects of interactions that were of interest in this study. Audio-recording provided a more accurate record of the course of the interview and allowed me to re-listen to the conversations as needed. Each audio recorded interview was transcribed in verbatim to assist the data analysis process. Furthermore, demographic data collected from questionnaires provided context for the verbal data from the interviews to paint a fuller picture of the participant's experience.

Type of Data

As previously stated, demographic data (Appendix C) collected include information regarding age, gender, race/ethnicity, hospital unit they currently work in, the number of years employed at the current hospital, and the number of years employed as a medical social worker.

Qualitative data (Appendix D) aimed to elicit descriptive data about the types of involvement oncology social workers have with cancer patients and their families, and how it may affect patients' decisions about end-of-life care. The interview questions

focused on the following three areas: 1) types and extent of involvement, 2) discussion about diagnoses, prognoses, treatment options, and implication on quality of life, and 3) discussion about death and dying. Interview questions were reviewed and critiqued by an experienced oncology social worker for clarity and revisions were made as appropriate.

Ethics and Safeguards

As participants' names could have been provided to this researcher through their colleagues or professional acquaintances, there is a possibility that others might know of their participation in this study. I maintained confidentiality in terms of what the participants had shared with me in the interview. I used numerical code to identify each individual's data. Participants' names and other identifiable information did not appear on the transcripts, my thesis, and its dissemination. If participants mentioned agency or other names in the course of the interview, I excluded such information from the transcript and other written materials thereafter. I was the only person who has access to the interview data in its entirety and I was the sole transcriber for all interviews. My thesis advisor had access to the transcript without any identifying information. In my thesis and any other presentation of the data, all quotes and illustrative vignettes were written in a manner that does not reveal information that could identify participants, patients, or any other names.

All data (notes, audio-recording, transcripts, questionnaires, etc.) will be kept in a secure location for a minimum period of three years as required by federal guidelines. The informed consent letter and demographic questionnaire remained separate from participants' interview data at a secure location. Beyond the three year period, data that I am not actively using will be physically destroyed by me.

The risks associated with involvement in this study have been considered. Individual social workers have different perspectives, unique working styles, and are faced with restrictions and limitations within various system settings. Questions in this study were expected to illicit a reflective process but they were not intended to critique participants' behaviors or experiences. However, some participants may feel embarrassed, uncomfortable, or inadequate when being inquired about their personal clinical practice. To minimize risks associated with possible emotional distress when discussing sensitive topics during the interview, participants were reminded they have the option to decide not to answer certain questions that provoke intense anxiety or discomfort.

A potential benefit for social workers to participate in this study is to have an opportunity to reflect on and to share their rich experiences of working with cancer patients and their families. Participants may gain deeper insight into these experiences and be able to incorporate these insights into their future clinical practice. In addition, participation in this study offered social workers the opportunity to contribute their valuable perspectives to the overall body of knowledge on how to better serve individuals with serious and life-limiting illnesses. Participants received no monetary or other material compensation for their participation in this study.

Data Analysis

A digital recorder was used for each interview to collect narrative data. I also took notes in a note book to write down my thoughts and observations. After each interview, I wrote down my impressions about the interview. I transcribed each interview verbatim in a word processing document to help me recognize themes and

organize data. The content analysis of the narrative data was thematic. The analysis was guided by the *grounded theory* method using a combination of *open coding* and *selective coding* technique. The open coding allowed me to identify different meaning units and themes that emerge as important from the perspectives of participants. The selective coding highlighted thematic categories relevant to a particular topic area. My hope was that the thematic results will highlight barriers that interfere with oncology social workers involvement with patients and families, and to generate recommendations at a policy and clinical practice level to improve services and continuity of care for people with serious and life-limiting illnesses. The data will also illuminate examples of the best practices that are currently being implemented.

Limitations of the study

There are potential limitations to the chosen methods. Due to the small sample size, the study findings were not generalizable beyond the sample group. In addition, even though strong attempt was made to maintain an objective stand, I do carry my own bias around this topic and my questions therefore might be phrased in a way that may cause me to overlook certain important aspects of the phenomenon. Limitations such as these will be discussed further in the exploration of study biases.

CHAPTER IV

FINDINGS

Following the approval of the Human Subjects Review Committee, the study was conducted over a three-month period. Sixteen oncology social workers were contacted through a snowball sampling process. Ten participants agreed and participated fully in this study. Participants filled out a demographic questionnaire, and signed an informed consent letter prior to participating in a semi-structured interview with me. The average participant age was 50.5 (range 33-63). All were white; the majority (n = 8) were female. All had Master in Social Work degrees, but their years of experience varied. Two had less than ten years, four had 10-19 years, two had 20-29 years, and another two had over 30 years (mean = 17.6 years). Participants' experience in the area of medical social work also varied. Three had worked as medical social workers for less than ten years, three for 10-19 years, two for 20-29 years, and three for over 30 years (mean = 16.8 years). The majority of the participants (n = 7) reported working at their current oncology position for less than six years (range 2.5 to 6), while two reported 20 years, and one 30 years.

Of all the hospital units that were listed as sites of employment, the following were mentioned: general oncology, hem-oncology, brain tumor cancers, gastro-intestinal cancers, head/neck/oral cancers, acute leukemia, bone marrow transplant, lymphoma/myeloma cancers, and sarcoma cancers. A third of the participants covered

both hematology and oncology units, while a third focused in hematology units, and a third in oncology units exclusively.

One question that was not included in the demographic questionnaire, but has significant influence on the level of social work involvement, was the type of practice model that the hospital utilizes (geography model versus continuity of care model). Geography model implies that social workers are assigned to one or more designated disease units and work exclusively with those patients, while continuity of care model implies that social workers follow their patients throughout their care in the hospital regardless of what unit they go to. Half of the participants operated within each practice model. Six of the participants worked in both in inpatient and outpatient settings, two in inpatient only, and two in outpatient only.

Eleven themes will be further explored in the following section: (a) referral patterns of cancer patients to social workers, (b) description of social worker's role, (c) degree of social worker involvement, (d) family meetings, (e) the ways social workers track their returning patients, (f) medical information discussions between social workers and cancer patients, (g) the need for social workers having medical discussions with cancer patients, (h) the effects of social workers discussing medical information with cancer patients on patients' end-of-life care decisions, (i) discussions about death and dying between social workers and cancer patients, (j) barriers to death and dying discussion, and (k) barriers to timely hospice referral.

Referral Patterns of Cancer Patients to Social Workers

Medical organizations often include very large networks of professionals serving a variety of functions. Participants reported that most patients and families often interact

with the following members of the interdisciplinary/multidisciplinary team: primary oncologist/hematologist (n=10), social worker (n=10), nurse practitioner (n=8), inpatient nurse (n=7), and inpatient attending physician (n=6). Other team members that were mentioned include fellow (n=4) and nurse case manager (n=4).

In addition to the primary treatment team, other providers that patients come in contact with depend largely on the disease type, treatment type, and whether they are in an inpatient or outpatient setting. The four treatment teams that were mentioned include the chemotherapy team (n=5), radiation team (n=5), surgical oncology team (n=3), and palliative team (n=2).

At least three of the participants mentioned that patients and families have frequent contact with the following auxiliary staff: physical therapist (n=4), nutritionist (n=3), respiratory therapist (n=3), chaplain (n=3), front desk staff (n=3), physician assistant (n=3), and volunteer (n=3). All participants emphasized the importance of the team approach. Two participants pointed out that the interdisciplinary/multidisciplinary team can get quite large and it may initially become overwhelming for patients to have to interact with so many different people. Keeping things manageable and consistent by offering on-going social work support and guidance seem to be a good way to help patients contain their anxiety and to maintain a sense of control throughout their treatment.

Even though everyone can refer patients to social workers, participants reported referrals were mostly initiated by nurses (n=6), physicians (n=6), and patients (n=3). Participants mentioned that those who spent the most time with the patients and their families ended up being the ones who made the referrals to social workers. Some

participants mentioned that in an inpatient setting, especially at a teaching hospital, the medical team rotates frequently, so the most consistent staff members for the patient ended up being the floor nurse, the nurse case manager, and the social worker.

Hospitals have various systematic approaches to the issue of when a social worker enters the treatment course of any given patient. Often times, the types of illnesses being treated dictates the timing, in this study, four of the participants reported that certain diseases or treatment types such as acute leukemia, bone marrow transplant, and biologic treatment have full social work coverage at the hospital where they are employed. Interviewee Four described what the typical onset of acute leukemia looks like and the needs for support from the beginning:

For us, we are there from day one. The onset of leukemia is very sudden. People don't have time to be at home processing it. For example, someone was sick on Monday and didn't feel good. They thought they had a flu, went to the doctor, and did some blood work. And immediately, they were admitted to the hospital and they are not going to work for at least eight months, if not a couple of years. So they are in shock. They virtually have no time to tie up loose ends at home or to plan anything. So with the emotional crisis for the patient and the family, we are very involved with family work.

In addition to disease type, there are various circumstances under which referral are being initiated. The following are the most common circumstances according to this study's respondents: psychological distress/emotional support (n=7), change of disease status such as recurrence, complication, or end-of-life issues (n=6), new diagnosis (n=5), and resource needs (n=4).

Half of the participants (n=5) did not think that there is a relationship between stages of disease and the time of referral. Interviewee Five noted that stages of disease might have different implications for different disease types:

I get people all across the spectrum. I work in breast cancer and that probably has something to do with it. As cancer goes, breast cancer is usually one of the better cancers to get. For most women, they are treated for months and never have to deal with it again. Or if it does come back, it's still a good chance that they live with the disease. So there is just more time. Whereas some other hideous cancers that are diagnosed, you have 6 months to live and so it's very pressed.

However, three participants did think there is a relationship between disease stage and referral, as Interviewee Six said, "I think the sicker somebody is, the more they get referred."

All participants seem to state or imply that there are certain predictable crises that most cancer patients go through and it's helpful for a social worker to be present.

Interviewee Eight explained,

Probably the two ends of the spectrum, around diagnosis, when it's all brand new, people are terrified and overwhelmed, and at the end when things are starting to decompensate and getting worse. In the middle, many patients will get over the initial shock of the diagnosis, get into a rhythm of the treatment if they are tolerating treatment fairly well, and there aren't other psychosocial stressors in their life, then the mid-phase can coast through. The diagnosis and end-stage are the two trigger points.

Finally, all participants agreed that most patients can benefit from a social worker at various points of their illness, but the reality is that there are not enough social workers for full coverage. Interviewee Eight commented,

It's worth pointing out that with the reality of staffing being what they are. There's a very high volume of patients here and there's only so many of us in the social work group. It sort of varies from disease center to disease center, but across the institute on average. It's only about 10 to 15% of the patients are followed by social workers. What that often means is that the folks who have more acute needs are the ones being hooked up with social work. So end-of-life issues are a common reason for referral.

Description of Social Workers' Role

Most oncology social workers (n=8) in this study introduce themselves to patients as members of the treatment team. Following are the seven most frequently cited

responses that social workers used to explain their roles to patients: Assist patients to cope with their illness (n=9), provide emotional support including counseling and therapy (n=8), be available to families and care givers (n=7), help with concrete resources (n=7), validate the experience of living with cancer and offer perspectives (n=5), address reasons stated by referral source, (n=5), and ask patients how social work can be helpful to them (n=3). Interviewee Eight offered this example:

“Whereas the doctors and nurses are focused on your medical care, your physical symptoms, and managing your treatment here, my role in the team is to help you and your loved ones cope with the other ways that having cancer affect your life.”

The way social workers introduce themselves appears to be different depending on whether there’s a specific reason for the referral versus a general referral. Some participants (n=4) mentioned the importance of clarifying the role of social work, because there are common misconceptions that may induce fear such as being identified with the department of social services or psychiatry.

Three participants mentioned that it’s common for the team to introduce the role of social worker to patients prior to their initial meeting. Even though concrete resources such as transportation, housing, and benefits were something that was mentioned to patients by many participants, it was emphasized that their focus is to address patient’s psychological and emotional well-being in the context of their illness. All social workers in this study connect their patients with a community resource specialist who works with them on their concrete resource needs. Interviewee Four described,

I will describe my role to patients like this, “About 95% of my role is for support and counseling when you’re dealing with a diagnosis like this both for you and your family, because it comes out of nowhere. It can be very overwhelming and people need support and counseling through this even just to help you to cope with this. About 5% of my role is to talk about some of the concrete services that

would be available to you such as..., just some of the things that will affect your daily life.” Predominantly, our role is there as a counselor to help them through this.

One benefit to offering a more general social worker role description is that it creates a “catch all” identity that is available to address all possible needs. However, one disadvantage may be that people are confused about what a social worker actually does and may not utilize the services as a result.

Degree of Social Worker Involvement

Over half of the participants (n=6) stated it was difficult to come up with an average or estimated number of sessions that they have with patients. Most participants mentioned that it depends on a patient’s need at the time (n=8) which may include the types and intensity of treatment they are receiving, predictable crisis events, coping, and support system. Others reported that the frequency of the meeting varies from a one-time meeting for resource or crisis intervention, one to two times a month in an outpatient setting, one to three times a week for patients receiving radiation therapy, to 10 sessions throughout the course of their treatment. For acute leukemia patients who have a more clear treatment protocol, three participants have responded similarly that they tend to taper the number of meetings from three times a week during weeks one and two of their treatment, to two times a week during weeks three and four, and to one time a week during weeks five and six. However, there are many unexpected events throughout the course of treatment that require social workers’ support. Interviewee Four explained,

On average, leukemia will have seven admissions when things are going well. You follow people for a very long time. The first admission is around 4-6 weeks. Consolidation treatment for follow-up chemo is 6 days. Most people end up back with a fever between the consolidations anywhere from a few days to two weeks. Then I see them in clinic at various points and I see them for follow-up. So it’s

hard to put a number on them. Patients of mine for two or three years down the road might page to see me if they are coming in, just for a quick little check-in. But for the clinical work, you follow them through their whole illness. Probably half of my people then at some point will go to a transplant, where they're in for another 4-6 wks. That is a very long difficult recovery period with a lot of medical or emotional complications so you stay involved during that period of time.

For some treatments, social work involvement varies based on the nature and intensity of the treatment. As Interviewee Three noted,

With my head and neck patients, the treatment is so difficult that it's hard for them to do individual counseling while they are getting their treatment, because their mouth and their throat are so damaged by the radiation and they are so uncomfortable. I think those patients, I start seeing them after they finished the treatment, when they are sort of feeling more disconnected from the team and they are starting to feel those emotions that they probably blocked trying to get through the physical part of the treatment.

One social worker pointed out that the financial state of the health care system resulted in reduction in staff and services dictates the reasons of referral. The lack of social work availability in the hospital influences the amount, types, and quality of work they have with patients.

In summary, patients' needs occur at different times and to varying degrees. Not all patients need social workers, but offering social work services in the beginning of treatment allows time for relationship building and creates a welcoming environment for accessible support for those who need it. Having a trusting relationship is the foundation for in-depth personal sharing to allow meaning making process to take place. Early social work involvement seems to be a reasonable and effective approach to offer to all cancer patients.

Family Meetings

In terms of family involvement, a majority of the participants (n=9) valued family involvement and reported family meetings happen “quite often” and “almost always.” Four participants reported that they work with many families by phone. Three reported they do a lot of work with couples, and will meet with the spouse and other adult family members separately and together as appropriate. Some of the key concepts mentioned by participants were that cancer is a disease that affects the whole family and that family members can feel especially helpless. For some disease types such as brain tumors, it is especially crucial for those patients to have sufficient support due to their cognitive deficits. Interviewee Eight explained,

The brain tumor patients are often somewhat compromised, may have some short-term memory issues, maybe speech problems, maybe other deficits where having someone with them is almost essential because there are important things being discussed in the meeting. They might not retain or remember it or have the ability to keep notes.

While families can offer practical and emotional support to patients by sharing the burden of making difficult decisions, their involvement can also make the treatment process more complicated. Interviewee Nine stated,

Everyone on a team has different feelings about when it [comfort care discussion] should be brought up and those conflicts. And that’s exactly the same model for a family. So stepping into a place where there are so many conflicted feelings sometimes isn’t even fruitful.

The Ways Social Workers Track Their Returning Patients

Regarding notification of returning patients, many participants (n=6) reported that there’s no official system in place to automatically notify them. The majority of the participants (n=7) reported they keep track of their own patients by referring to the hospital daily census. most participants (n=7) mentioned they work very closely with the

team and that they are likely to get a “*head-up*” from physicians or nurses regarding known patients returning. However, participants also emphasized that it’s not necessary to see every patient at every medical appointment. Half of the participants (n=5) stated it’s not uncommon for patients to call them when they are back in the hospital for treatment. Four participants reported they have weekly team meetings to go over each patient who is coming in for treatment. There seems to be different tracking systems for inpatient and outpatient settings. The size of the disease center also influences the likelihood of returning patients being identified. Smaller disease centers tend to have more informal communication. Social workers are likely to be involved at crisis points during the treatment course such as waiting for and receiving test results, recurrence, complication, and disease progression. Interviewee Three mentioned,

If a patient has recurred, or has progressive disease, it’s likely I will know about it. If the patient hasn’t told me, the team will likely mention it in the team meeting or the nurse practitioner will tell me. That’s such a huge part of a patient’s illness, the fear of recurrent and the progression of disease.

Social workers working in a geography model tend to collaborate with social workers on other units by referring to their medical notes and communicating by phone for other necessary information. Overall, it doesn’t seem to be a problem for social workers to track existing patients who were already connected with social work. However, patients who appeared to be coping “well” and were not connected in the first place are more likely to fall through the cracks when they begin to experience difficulties.

Medical Information Discussions between Social Workers and Cancer Patients

Four participants in this study reported they have been actively engaging with patients and families on discussions about patients’ diagnoses, prognoses, treatment

options, and their implications for quality of life, while the rest (n=6) mentioned it depends on the circumstances. Nine participants stated or indicated that having a trusting relationship with the patient is a crucial ingredient for allowing the medical information discussion to take place. Interviewee Four stated,

I'm completely involved. When I first meet people, in my first hour and a half the time I spent with them, I ask them to tell me exactly what happened that they ended up here. Because I like to hear from people what they had gone through. Everyone's story has similarities, but different. It just gives you an appreciation for what it's been like for them emotionally to get to this point.

Instead of automatically initiating these conversations, social workers (n=6) reported they will take the cue from patients on their readiness to explore certain information. A common way to approach the topic reported by many participants (n=6) is by learning about patient's understanding of their own illness.

One of the frequently reported factors that determine the likelihood of such discussions taking place includes social workers' sense of competence on the topic area (n=6). Interviewee Seven described,

I think the more you work in a particular area, the more you have an understanding of it. And then, you know your doctors and you know how they operate, so it's pretty easy to make some clarification.

Another factor that helps to facilitate this discussion is when physicians include social workers in their meetings with patients (n=4). Interviewee Eight noted,

I also think that for those patients that I'm seeing at their first visit here, processing it with me afterward can be really helpful, because in the meeting you are so anxious, overwhelmed, so much information coming at you all at once, and the doctors don't have time to go over and over again the same information. When we are all in the same room together hearing it for the first time, I can follow-up with the patient and their family after the meeting or the next day, or later that week, and we can process it.

For social workers who do explore or clarify medical information with patients, some (n=3) emphasized they are careful to remind patients that the explanation or sharing are their own non-medical opinions. In addition to not wanting to overstep the physician's role, the fear of misinforming patients reported by two social workers seem to illuminate a major reason why some non-medical providers are hesitant to be more involved in this process. Although physicians might not have the availability to meet with their patients for a long time or to repeat information over and over, four participants suggested nurses often do a good job filling the gap by providing concrete medical information to patients regarding their treatment.

The topic of hope came up as social workers reflected on their role discussing medical information with their patients. Three participants suggested the discussion needs to be carried out in the context of hope and patient's readiness. The motive of helping patients to stay hopeful seems to both promote and discourage some participants from focusing on prognostic information. Interviewee Two stated,

I don't see it as my position to say this is your diagnosis, this is what's going to happen, this is what the study shows in terms of your disease, and this is what treatment is going to be like. What I will talk about is their uncertainty about whether they should have hope.

It's not uncommon for people to utilize their psychological defenses in order to sustain a hopeful attitude. Therefore, it is necessary for providers to have the sensitivity and respect for the functions of these defenses. Interviewee Two said,

There are some people who engage in denial. This is a defense mechanism and you sort of have to recognize that as such. I think we have to identify it up front and remind staff, "You don't have to hammer up against that denial and let time do some work here." Sometimes people engage in a certain amount of denial at least early on in all of these, in order to get through certain phase, but then as they

evolve and develop more relationships and they start to hear more, they may become more comfortable with the discussion.

What seems to be helpful for patients is to offer them perspectives in the context of their illness that preserve hope while gaining insight and tools to cope with their difficulties.

Interviewee Two continued,

I will remind them that hope comes in all shapes and forms. In other words, “Are you hoping for cure? Are you hoping for a year? Are you hoping for three more months? Are you hoping to be here next week for your daughter’s graduation?”

Interviewee Ten added,

People often quote statistics, “The doctor gave me 40%, the doctor gave me 60%, this is the best kind of cancer to have, or this is the worst kind...” You know, they are just numbers. I tell them that people are individuals. For them, we want the treatment to work a 100%. Somebody has to fall into that 40% category. So I really don’t like the number so much. As time goes on, let’s say the cancer does not respond to treatment after treatment, then that’s a little bit different. But initially, there’s no reason why people shouldn’t have a lot of hope that the prognosis is good. That’s why they are getting treatment.

Again the nature of the disease and treatment seem to affect how the discussion about medical information takes place.

The Need for Social Workers having Medical Information Discussions with Cancer

Patients

While most social workers (n=8) reported there is a need for them to be involved in this discussion process in some way, four participants stated they would defer the medical discussion to the physician and five participants emphasized their role of facilitating communication between the patient and the rest of the medical team is the key. Most of the participants (n=8) mentioned the goal of the medical discussion is to allow patients to be heard and to understand patients’ interpretations of their illnesses and experiences. Interviewee Six said,

I think it's important to hear the patient and family's interpretation of what their doctor has said. I do think it's important because I believe there could be misunderstanding, there could be cultural differences that people miss, or just a lot of information that someone might not understand.

Half of the participants (n=5) mentioned or indicated that physicians and nurses have anxiety about communicating unfavorable prognoses to patients and that could contribute to their reluctance to have an open and honest discussion about possible options. In that sense, social workers might be in an ideal position to help bridge the gap to facilitate patients' understanding. Interviewee Five said,

In some ways, it's easier for social worker because I don't feel responsible for curing this person. My only job is to be here to try to make it least difficult and painful as possible. Whereas the physicians and nurses to some extent have a whole other agenda they have to keep their eyes on trying to fix it or to cure someone.

Participants described a crucial role of being a medical social worker is to help patients and families process their experience and decisions around the illness (n=7).

Interviewee One noted,

Social work is crucial because social work is process. Nobody arrives at a comfortable and honest position without process. It's not my job to deliver the good news or bad news, but it's my job to help the person process.

For the most part, participants (n=6) reported that patients have a clear understanding of the medical information, but patients may have different degrees of understanding. Three of those participants specified exceptions to the circumstance such as pre-existing psychiatric conditions, cognitive difficulty, or extreme emotional vulnerability.

Most participants believe that there are three important factors that help improve patients' understanding of their medical conditions: The medical team's effort in repeating information (n=7), encouraging questions from patients and families (n=7), and initiating questions (n=4).

Regardless of having an overall cognitive understanding of their medical condition, most participants agreed that patients have to overcome tremendous psychological obstacles that may interfere with their ability to fully comprehend the amount of information and their implications. These difficulties include anxiety and being overwhelmed (n=7), defenses (n=6), and that it takes time to psychologically come to terms with a cancer diagnosis (N =4). Interviewee Ten explained:

I think that initially people are very overwhelmed, and they just can't hear it. It's like this wave that comes over them when they are basically gasping for air. As they move through the process, the nurses on the floor are terrific in explaining things, so people little by little get information and I really do think it's important that we compartmentalize and simplify things for people. But I think initially, it's a very difficult and scary time.

Interviewee Nine added,

I think many times they don't have clear understanding. I think often times they have cloudy lens and defenses, so they may actually be told very clear information and may not hear it, or doctors are avoiding as well and they may not impart information. Doctors have their own anxiety, so do the nurses. Social worker can often come in and bridge that gap.

Physician's communication style (n=4) and the amount of information given (n=4) were also reported as factors that may either help or hinder patients' overall understanding. Their styles are likely linked with their comfort level and skills around communicating poor prognosis, as mentioned earlier. Information is sometimes given in pieces or compartmentalized to prevent patients from being too overwhelmed; on the flip side, patients and families may have difficulty preparing emotionally and practically for what lies ahead. The withholding of information may also create resentment that could affect the level of trust that is essential in a physician-patient relationship. Interviewee Five said,

I think people who are very ill do not necessarily have a clear understanding about end-of-life care. It is partly because our doctors sometimes consciously or unconsciously collude with patients of not talking about how bad things are. Doctors are quick to say there's one more treatment, even though it may be clear to the doctor there's a 2% chance of being helpful. It's unusual but not unheard of, for me to be the first person who has a conversation with the patient about "you're going to die from this illness."

Unfortunately, as reported by two participants, the risk of miscommunication increases when factors such as language, culture issues, and education level come into play.

Three participants said straight forward treatment protocols and goals, and close follow-up allowed patients to have a clear overall understanding of what to expect.

Interviewee Four described,

With leukemia right in the beginning the goal is to cure. The prognosis obviously can change, and people don't always get into remission. From my experience, the inpatient nurses just go over things. The doctors see them every day, there's a team that follows them in the hospital, and their own doctor comes over, so it's something that has to keep being talked about because people sometimes shut-off or they only hear things as opposed to something a little bit different. So I see it as an on-going process that they have.

In terms of the treatment team's response to social workers clarifying medical information, all participants reported that the team responds favorably. Factors that were reported to enhance this process include working closely with the treatment team (n=6), having a trusting relationship with staff (n=6), years of experience in the field (n=4), and having a practice environment that views social work as an integral part of the medical team (n=4). Interviewee Seven said,

We are a very close team. They won't do this without us, and we obviously won't be able to do this without them. Social work is a very integral part of the team. We are actually highly valued and we are pretty essential in the whole scope of thing.

The Effects of Social Workers Discussing Medical Information with Cancer Patients on

Patients' End-of-Life Care Decisions

In terms of participants' views on how medical information discussion may affect patients' ultimate end-of-life decisions, six participants reported it can be helpful. Seven of the participants reiterated that it was the social worker's role to provide on-going assessment on the evolution of patients' readiness, understanding, and coping with their illness. Patients' priorities and decisions are likely to change as their illness progresses. Participants' responses reflect the importance of having consistent support for the patient and their family early on to allow on-going difficult discussions to take place.

Some participants (n=4) mentioned that social workers play an important role in helping patients to explore their experiences because some patients may be uncomfortable expressing their fears or worries to their physicians and not wanting to contradict physicians' advice to continue with treatment. Social workers can provide support and advocacy for their patients and offer insight for the treatment teams to ensure true communication takes place. Interviewee Two said,

Some patients want to do well in front of the doctor and don't complain or won't say, "This is wrong." They want to present a good picture and want to be a good patient. They may be more honest about their struggles with us or with the nurses.

Three participants indicated that it's important to strike a balance between preparing the patient without overwhelming them. Some patients become overly worried about their futures and their anxiety makes it difficult for them to cope with the present. Other patients are kept from seeing the whole picture and they are unable to slowly digest the information or to prepare themselves and their loved ones. In those situations, social workers need to know when to encourage patients to be mindful of the present and not to get ahead of themselves, and when to encourage physicians to offer realistic prognostic

information so that patients and families can make informed decisions. Interviewee Two mentioned,

I try to remind patients that this disease is new for you, but it's not new for us. The team has been through this with other people. Let us help you. Sometimes people do relax when they realize they are not quite alone and there are other people who can help them understand their disease and what to do when the time comes.

The goal of the treatment, the culture of the disease unit, and characteristics of the patients seem to directly affect when and how end-of-life discussions are being brought up. For example, some participants (n=3) described bone marrow transplant as a lengthy and vigorous procedure where patients end up having very close connections with staff members because of the amount of time they spend in the hospital. Interviewee Seven described,

We may refer to the hospice maybe not even five times a year. We rarely use palliative care. The transplant program does it themselves. If the patient does become very ill after the transplant, even during the transplant, looks as if they are going to die, they are most likely going to die in the hospital either in the ICU or on the transplant unit. If they are being readmitted, they often tend to want to die with the same people who had transplanted them. So end of life decision comes toward the very end, it's never talked about in the beginning, because it seems as a very long road, so end of life care comes at the very end if and when it happens.

Discussions about Death and Dying between Social Workers and Patients

All participants reported discussions about death and dying do come up with most patients and families at some point, as Interviewee Two explained:

The best way to describe it is it gets visited with almost every case, but to a different degree of intensity. In other words, you are not talking about death and dying, but you are talking about their thoughts around death and dying.

The way these conversations are being initiated and under what circumstances vary. The majority of the participants (n=7) agreed that this discussion needs to be initiated by the physician or medical team. Interviewee Eight said,

Most often than not, it's going to begin with the medical team. Often the oncologist or the nurse practitioner, because they are the one who are going to review the MRI scan, the lab report, or whatever the indicator that's going to give us the data to say the cancer came back, or the cancer progressed, or things are getting worse.

Half of the participants (n=5) stated patients will often initiate or allude to the topic. It was also reported that sometimes the medical team will present the prognostic information, and have the social worker provide emotional support afterward. Unfortunately, the lack of collaboration or insufficient staffing could lead to situations where the social worker steps in the situation too late. Interviewee Six described,

At times, because of the lack of the number of social workers, I get called in to things at the very end point, so I haven't gotten to spend time with them to build up that relationship. So, not enough.

Common circumstances during which these conversations take place include when all treatment options have been exhausted (n=5), noticeable changes in patient's health status (n=5), new diagnosis (n=4), and poor response to current treatment (n=4). Interviewee Three described,

I get involved in this discussion when there are significant changes. For example, someone who previously could breathe on their own now they need to wear oxygen; someone who's sleeping more hours in the day than they used to; someone who despite going to terrible treatment, everyday they got up to walk their dog, one day they don't get up and walk their dog because they just can't do it.

Social workers can hold the hope for their patients while exploring their fears and preparing for the reality of the situation. Interviewee Four explained,

They come here with hope of good treatment but that fear never really leaves them. They're hopeful for cure and that everything is going to be fine, but they might still talk about their worse fear: "If I die..." or "My little kids..." You are talking about it, but it doesn't mean you are going to die.

Consistent with the responses to previous sessions, participants (n = 4) reported different disease types affect when and how this conversation take place.

Some of the ways the death and dying discussion are being facilitated include by open-ended questions (n=8), referencing physicians' prognostic information (n=6), taking cues from patients (n=5), exploring patients' fears and worries (n=4), normalizing the experience as a life cycle event (n=4), spirituality (n=3), and patients' experience with death and with cancer (n=3). Interviewee Two said,

I think a safe way to bring up this is to say, "It's my experience that many patients do start thinking about dying or many patients do think about their experience of dying." I will use that as a way to say, "Not that you are thinking about it, but I certainly hear plenty of other people who do think about it." It sort of helps normalize the topic and give them permission to do so.

Participants reiterated that the death and dying discussion needs to be rooted in an established relationship (n=7). Interviewee Three stated,

It's easier when it's a patient I've known throughout the process. Then I'm pretty open with talking about it and I feel more comfortable bringing it up. I've also been in the room when the physician and the nurse practitioner have approached the subject with the patient, and then the physician might leave the room and I'll have time to talk about the emotion of it.

Some participants (n=4) mentioned that although most people dread having this conversation, ironically, a benefit of having it is that it may ultimately help patients to alleviate patients' anxiety (n=4) and feel less alone (n=2). For those participants who have this view, they seem to be more willing to take risks around this topic. Interviewee Two noted,

If someone is talking about something and giving you an opening, and you really want to go there, chances are, they are also looking to explore it. Sometimes they are looking to us to introduce it and they want us to take a chance. If I'm really off the mark, they will let me know and we won't go there. But I take the burden off of them for bringing it up. So much is upon how long I have known them,

what the relationship has been like, and do I know the nuances of their relationship.

In terms of whether this conversation will be revisited if patients declined to discuss it initially, all participants (n=10) answered yes in one form or another. The top three circumstances that were reported include as the illness progresses (n=5), through on-going conversation and addressing what the patient might be alluding to (n=4), and by the medical team bringing it up (n=3). This discussion takes place as an evolving process. Interviewee Five shared,

One woman who I see pretty regularly came in one day talking about how appalled she was that recently when she's been on the bus, people have stood up and offered her a seat. She said, "Do I really look that sick?" I sort of swallowed hard and said, "Yes." And that started the conversation which she's been never able to have before. After I said, "yes," she started to cry and sat down and then she began to talk about, "I tried not to see that, but I guess I really am sick and I'm really scared." And then it just sort of went... But then she and I knew each other pretty well so that makes it easier. It would be much harder to say to somebody I don't know, "Yes, you look that sick," because that's really insulting.

Some participants (n=3) also emphasized the importance of respecting patients' defenses and not persisting with their own agendas. Interviewee Eight said,

The phrase "In denial" gets tossed around a lot. "You go fix that problem." Ninety-nine percent of the time what is being labeled as denial is a very healthy appropriate way of that person gradually coming to terms with something. So if someone is not ready to talk about death and dying, rarely it's appropriate to push that issue, and rarely it's appropriate to challenge someone's denial.

Barriers to Death and Dying Discussion

All but one participant (n=9) identified some sort of barrier to this discussion. The four most frequently cited reasons include the physicians' reluctance to bring it up (n=7), patients' or families' reluctance to talk about it (n=5), focusing on health and treatment (n=4), and social worker's difficulty approaching the topic (n=4). Patients' and families' reluctance might be easy to understand, because they are sad, scared, and want

to remain hopeful. Some of the underlying reasons behind physicians' anxiety are as follows. Interviewee Eight said,

This hospital is committed to eradicating cancer and to finding a cure. That's central to the mission. It's also central to the mission that we provide care and support for our patients regardless of the outcome. Patients come here for options when they ran out of options everywhere else. Providers and physicians and nurses come here because they want to help people fight. So there's an institutional mentality.

Interviewee Five described,

My guess is that the providers don't want to talk about it for two main reasons. One is that they feel like a failure. Doctors are supposed to fix things and cure things. The second being that that they are afraid that there's going to be an emotional implosion and they won't know what to do about it. There are doctors who are really uncomfortable with someone sobbing in my office, so they just don't want to get into it. Or it could be internally upsetting that it hits off their own issues about mortality.

Social workers' views on how the death and dying discussion can be helpful to patients include weighing out options (n=4), reducing anxiety and providing feeling of relief (n=4), and providing modeling by normalizing this discussion (n=2). Interviewee Eight said,

Certainly my role in these discussions helps to make sure that the patients and their loved ones are aware of all the options that they are then given permission to consider all of the options including transitioning to a more palliative and comfort care approach.

Three participants suggested the death and dying discussion should be an on-going process because patients' understanding about their condition changes and their decisions change as their illness progresses. Interviewee Four recalled that a patient said, "Until you are standing at the edge of that cliff, nobody can say what you're going to do." Having a trusted person to guide and support through this journey can be invaluable for the patient to gain perspectives about their experience. Interviewee Nine described,

I think [the discussion about death and dying] affects [patients' end-of-life care decisions] positively. I think that there's a certain amount of emotional psychological preparation. I think it reduces anxiety and fear. I think it makes people feel less lonely. I think it helps people take more chances and avail themselves of comfort care. It doesn't make them alone in the darkness so to speak. And doesn't make them feel like somehow they are pathologically depressed. They are not being labeled as having a problem or being suicidal. They are expressing something very natural and they need people around them that can safely discuss things with them openly. I think it would be a much more positive outcome.

Barriers to Timely Hospice Referral

One question that explored participants' observations on barriers to timely hospice referral elicited the following top five responses. Half of the participants (n=5) mentioned physicians' reluctance to bring up the topic as a factor. Interviewee Eight pointed out a dilemma some physicians face,

I do think that many physicians still feel like it's not time to refer, they delay it, and they are very uncomfortable particularly if patients are ambulatory. Basically the healthier the patient seems and the higher their level of function, the more ambivalence a lot of the physicians have. [They'll say,] "I don't think it's quite time yet."

Four participants reported it was due to the general public's lack of understanding or misconception of hospice. Some participants reported patients' and families' resistance in discussing end-of-life care issues either because of their attitudes of wanting to stay hopeful and to keep trying (n=4) or their lack of readiness (n=3). Finally, three participants reported the fact that some hospices do not cover certain active treatments which prevent some interested patients from pursuing comfort care options. Interviewee Five explained,

A big factor has to do with medical insurance. Different hospices have different kinds of contracts with different insurers with different sets of rules about whether somebody can still be receiving any kind of active treatment. And there are people, for example, in radiation therapy for pain control for bone metastasis, and

there are some hospices which can work with that and there are others that can't.
So there may be real reimbursement reasons where it's not possible.

CHAPTER V

DISCUSSION

The purpose of this study is to explore oncology social workers' level of involvement with cancer patients in a hospital setting and the effects this involvement might have on patients' end-of-life care decision. A cluster of questions in the first section of the interview aimed to understand the process by which cancer patients are referred to oncology social workers and the extent of their interaction. Once a descriptive portrayal of how social workers function in a hospital setting had been established, the relationship between their discussions with cancer patients and families about medical information and death and dying and the effects they have on patients' end-of-life care decisions were explored.

The ten oncology social workers who participated in the study were selected through a snowball sampling process and interviewed using a semi-structured format. Thematic analysis around the three sub-questions helped determine the findings that were outlined in the previous chapter. In this section, I will explore the following key themes: (a) Cancer patients' understanding of their medical conditions; (b) Social workers' role in facilitating communication among cancer patients, families, and the medical team; (c) Importance of early social work involvement and on-going relationship; (d) The role of hope in treatment decisions; (e) Other barriers to timely hospice referral. The issues pertinent to each of these areas will be discussed.

In general, the findings from this study were reflected in much of the literature on working with individuals with terminal illnesses and also bring light to certain issues discussed in the literature on the physician and patient dyad and on the importance of social workers' early and on-going involvement. Literature has indicated that having a clear understanding of the medical information impacts patients' ability to make informed treatment and end-of-life care decisions. However, a major finding of this study is that there are other factors besides medical information that influence patients' ultimate treatment decisions. Having a trusting relationship with patients is a core ingredient to facilitate discussion relating to end-of life issues. Moreover, the discussion about death and dying helps facilitate the psychological processes and preparedness for patients to cope with their illnesses.

Cancer Patients' Understanding of Their Medical Conditions

In this study, most social workers (n=6) perceived their patients as having a clear understanding about their medical conditions due to the fact that physicians and nurses actively discuss medical information with patients throughout the course of their illnesses. This finding seems to contradict a number of studies (Butow et al., 2002; Cherlin et al., 2005; Clayton et al., 2005; Friedman et al. 2002; McGorty & Bornstein, 2003; Ogle et al., 2002; Sullivan et al., 2007) that have explored difficulties around communication between physicians and patients that may contribute to patients' not being fully aware of their medical conditions, thus preventing them from electing end-of-life care at an earlier time.

There are several ways to understand this discrepancy. First of all, most literature mentioned above focused on physicians' difficulty initiating specific types of medical

discussions regarding poor prognoses and end-of-life care with their patients. In this study, medical information has a broader definition that includes diagnoses, prognoses, treatment options, and implications for quality of life. Throughout the course of patients' illnesses, different types of medical information were presented to them at different times. There is a possibility that patients may have a clear understanding about their medical conditions in a broader sense up to a certain point until their health conditions deteriorate and then physicians may have a more difficult time being transparent and open about the poor prognostic information.

Another way to understand the discrepancy is that there are different levels of understanding that people achieve. Most participants (n=7) agreed that cancer patients endure tremendous psychological barriers such as anxiety, fear, and defense mechanism such as denial that may interfere with their ability to fully comprehend all the new information. This finding was consistent with the literature (Linder, 2004; Schroepfer, 2007; Ziberfein & Hurwitz, 2004) that described the psychological struggles of people faced with life-threatening illnesses. Patients' experience may fluctuate as their health conditions, functioning, life circumstances, relationship, and responsiveness to treatment change as their illnesses progress. Some people may initially understand their overall medical conditions at a more concrete level, but the emotional integration and meaning making process may require more time. As Interviewee One so articulately described,

I think people cognitively understand, but emotionally they may not take it in. They may not stretch all the way to the end of the implication. It's not a cognitive issue. It's a problem of your defensive constructs. It's a problem of your emotional capacities. But people understanding the words.

*Social Workers' Role in Facilitating Communication among Cancer Patients, Families,
and the Medical Team*

Our professional identity shapes our understanding about the roles we have in a given setting. All oncology social workers (n=10) in this study identified themselves as members of an interdisciplinary/multidisciplinary treatment team. The definition of such is a group of health professionals with different expertise working together as a team in shared decision making and with shared goals about patients' care.

The ways social workers position themselves in a team depend largely upon each member's area of expertise, expectations, and accepted behaviors within a given work culture. My speculation based on observation is that people might be less likely to perform duties that are outside their scope of practice and knowledge base. For example, a physician who feels less prepared to deal with patients' emotional outbursts around poor prognoses may be more reluctant to communicate such information or delay it.

Even though communicating medical information is not an official duty for oncology social workers, most social workers (n=8) agreed that it is their role to assess patients' understanding of their illnesses, and to facilitate communication among patients families, and medical providers. These findings were supported by Clayton et al.'s (2005) findings that allied health professionals such as social workers and nurses focused their role of exploring patients' concerns about their future, but would defer all medical discussions back to the physician. O'Donnell (2004) observed that social workers' early intervention can improve communication patterns, prevent miscommunication, and facilitate the process of helping patients to make informed decisions.

Most social workers in this study acknowledged that some physicians may have difficulties communicating honest prognostic information with their patients in a timely manner. It is interesting to examine how different social workers use themselves and the reasons behind how they choose to mediate such possible service gaps. While some social workers (n=4) reported they take an active role in helping patients to clarify and process medical information, others (n=6) emphasized that it depends on the circumstances. Those who feel strongly that it is the physician's role to discuss and clarify information are more likely to defer all medical questions back to the medical professionals. For those who play a more active role in helping to clarify and process medical information with patients, there seem to be two factors related to such an approach: 1) the number of years a social worker has been employed in a particular disease unit and 2) the physicians including social workers in their meeting with patients.

According to the demographic data, participants who reported taking an active role were those who have worked with a particular patient population for at least seven years (median = 19 years) and reported having a good trusting working relationship with the treatment team. Although this finding has not been addressed by the literature, one may speculate that those who feel more competent with certain medical knowledge may feel more comfortable having these discussions with their patients even though they were outside the scope of their practice. However, it needs to be emphasized that these social workers all pointed out that they were careful to inform patients that what they had shared was based on their own non-medical opinions and they would only speak to topics that they had sufficient experience with and knowledge in.

Friedman et al. (2002) also found that physicians who valued a collaborative and interdisciplinary approach to medicine were more likely to refer their patients to hospice services. Having a collaborative, trusting, and respectful relationship among the treatment team members seems to be key in promoting social workers' more active role in ensuring patients having a full understanding about their medical conditions. As Interviewee Two explained,

We've all been working here for a long time, people know our styles and they are not afraid to refer to us. They know we're not going to undermine them with the patients. So I think we all trust each other pretty well.

Importance of Early Social Work Involvement and On-going Relationships

When people learn they have a cancer diagnosis, they enter a very vulnerable time when there is much unknown ahead of them. The point of diagnosis is a scary time when people are immediately confronted by their own mortality. "Am I going to die from this disease?" Although half of the participants (n=5) did not think there was a direct relationship between stages of disease and the time of referral to social work, many social workers (n=6) in this study reported they were more involved with their patients' care as the patient's health conditions deteriorate. This finding was consistent with Zilberfein and Hurwitz's (2004) observation that patients often don't get referred to social workers until the end of their illnesses when they need palliative or hospice care.

In this study, participants suggested there were certain predictable crises that most cancer patients will encounter (i.e., new diagnosis, recurrence, complication, non-responsiveness to treatment, and exhausting all treatment options). All participants (n=10) indicated that most patients can benefit from having a social worker at various points of their illnesses. These findings were also supported by Linder's (2004)

recommendation that social workers' early involvement can help patients develop coping skills and strategies that they can use throughout the course of their illnesses. Social workers can also assess patients' preferred informational level as their illnesses evolved. Most participants (n=7) emphasized that difficult discussions such as death and dying need to be rooted in an established relationship. These findings were consistent with literature (Butow et al., 2002; Csikai, 2006; Schroepfer, 2007) suggesting that having a caring line of communication helps facilitate the process of assisting patients to address their emotional distress, which contributes to patients' perception of being heard and makes their situation more tolerable. In order to cultivate a trusting relationship that fosters deeper levels of interaction, social workers should be involved at an earlier time to support patients' evolving understanding and emotional integration of their illness experience.

The Role of Hope in Treatment Decisions

Several participants in this study suggested that the discussions regarding medical information or death and dying need to be explored in the context of hope. Ziberfein & Hurwitz (2004) pointed out that hope plays an important role in sustaining patients throughout the course of their illness. According to Garrett and Weisman (2001), as cited by Ziberfein & Hurwitz, without hope, self-cohesion may be compromised and other interventions (medical, psychological, social, and spiritual) may lose their effectiveness. Hope comes in all shapes and forms and it means different things to different people. With a more traditional medical approach, hope is often synonymous with cure (Ziberfein & Hurwitz). Therefore, some physicians may continue to recommend treatments until the very last moment in an attempt to preserve "hope" for the patient. On the other hand,

patients who were not fully informed of their terminal prognoses until the very end might be surprised by the unfortunate outcome because patients and their families may not have sufficient opportunities to psychologically and concretely prepare for the unavoidable ending.

To determine when and how much prognostic information to offer a patient, it is important to understand patient's subjective experience, instead of the provider's personal belief and clinical opinion, as a starting point. The meaning of hope and quality of life are subjective to each individual. It is not realistic to prescribe any one specific solution to all cancer patients without truly knowing their wishes, values, and beliefs. When people are being heard and decisions are being respected, the end stage of life can be made meaningful. As Ziberfein and Hurwitz (2004) cited, "In the context of hope, the focus at the end of life shifts from the attainment of long-term goals to the subjective meaning that can be derived from each remaining moment" (Herth, 1990).

Barriers to Timely Hospice Referral

Barriers to hospice referrals can come from the system level, the patient/family level, or the provider level. At the system level, some social workers reported the lack of education or misconception among the general public seems to affect people's attitude about bringing up hospice. As Interviewee Three described,

People usually do not react well when the word "hospice" is brought up. Whether it's brought in a positive way or not, our society has made hospice the dirty word. Hospice is the word that shows you're giving up, that you're going to die, or you have weeks left, instead of focusing on all of the great things that hospice can contribute to the end of someone's life or to their care.

In addition, this barrier was confirmed by the results of a NHPCO (1999) public opinion survey where 80 percent of the respondents from the general public did not know what

the word “hospice” means, and 90 percent were unaware that Medicare pays for hospice services. The outcome indicates the needs for additional education and awareness to the general public including medical providers about palliative and hospice services, which is consistent with Friedman et al.’s (2002) study recommendations as one of the ways to address barriers to hospice referral.

Another systemic barrier is that the low per diem rate for hospice benefits discourages some hospices from accepting patients who require on-going usage of expensive treatments such as palliative chemotherapy, palliative radiation, or blood transfusion. In addition, there seems to be a lack of standardized coverage regulations which creates confusion among providers and patients, and discourages referrals. Such systemic barriers prevent certain patient populations from utilizing hospice services while accessing necessary active treatments in order to sustain quality of life during patients’ last days. These findings were supported by McGorty and Bornstein’s (2003) comprehensive feedback from health providers and administrators about barriers to hospice referral. According to Casarett et al. (2006), some reasonable effort has been made to address such barriers. For example, veterans can now receive costly palliative treatments from the Veterans Administration (VA) Hospital that enables hospices to financially afford serving patients who require these types of active treatments. Medicare should consider incorporating such treatment coverage into their reimbursement plan so that more people could benefit from hospice care without having to immediately give-up life sustaining treatment, thus increasing their quality of life during their last days.

At the provider’s level, participants (n=5) reported physicians’ reluctance to bring up hospice as one of the major barriers. This finding was supported by literature (Cherlin

et al., 2005; McGorty & Bornstein, 2003; Ogle et al., 2002) that explored physicians' difficulties having discussions about poor prognosis and end-of-life issues with their patients. Some of the reasons include their curative orientation, their difficulty making prognostic time prediction, their view of stopping curative treatment (switching to comfort care) as a personal failure, their reluctance to engage in emotionally latent conversations, and their attempt to preserve patients' hope.

Finally, at the patient's/family's level, participants reported patients' hopefulness or lack of readiness as barriers to timely hospice referral. This finding was also supported by Weggel's (1999) study that explored reasons for untimely hospice referral. Humans' will to live is an extraordinary thing and it does carry people far. In addition to facilitating patients' understanding, social workers can play an important role in supporting patients' hope while addressing their fear and concerns. Interviewee One described,

You [Social worker] can promote the readiness, because you are in a relationship. If a person allows you to be in a relationship with them, hopefully there's a degree of trust and honesty in your discussions. And then things that matter to that person will be included in the discussions.

This Study's Strengths and Limitations

Strengths of this study are as follows. The qualitative method allows oncology social workers' deep reflective narratives to paint a vivid picture around current practice and the complexities of their interactions with both their colleagues and patients. Many of the social workers have worked a long time in the medical social work field and the depth of their experiences reflect the level of expertise that are invaluable to inform best practices to guide newer clinicians.

The interview questions in this study asked for details connected with the way social workers approach discussions about medical information and death and dying which have not been explored in existing literature. These data may set the foundation and provide an entry to future exploration in these areas.

This researcher's personal experiences of working in a hospital setting may have informed her ability to frame her interview questions, to follow-up up with participants' responses, and to have a contextual perspective to better understanding participants' experience within the hospital setting.

Some limitations of this research are as follows. The sample of ten oncology social workers is quite small and all were white; therefore, the results may have low external validity. The 10 oncology social workers represented four different hospitals and all worked in the same geographical region of Boston. There may be geographical differences in terms of medical social workers' role in Boston as opposed to other regions of the country.

Finally, even though this researcher tried her best to maintain an objective stand about the topic, her personal bias toward hospice services might have come out through the focus of her literature review and also what questions she chose to have her participants to elaborate. Her personal bias might have also caused her to overlook certain important aspects of the phenomenon explored in this study.

Social Work Practice Implications

The practice implications for social workers working with cancer patients are as follows. Both the literature and participants agreed that there are predictable crises that most cancer patients experience in the course of their illnesses. For social workers to

intervene at the point of diagnosis can help patients to prepare and cope with predictable obstacles. Moreover, at the time of crisis or major decision points, without an established relationship with the patient and knowing who they are, it would be difficult for the social worker to have an open honest discussion with them to process negative emotions and tough decisions. Patients' understanding and decisions about their condition evolve as their illnesses progress. Having a consistent support and on-going discussions with social workers can help address concrete and emotional difficulties as they arise.

As indicated by participants, having a sense of competence with medical knowledge for the population they work with contributes to social workers feeling more comfortable exploring medical information with their patients and assuming a more active role in facilitating communication. Social workers can familiarize themselves with medical knowledge by researching topics on the internet, consulting with their medical colleagues, or attending hospital in-service training to update their knowledge.

Policy Implications

First of all, having sufficient staffing is the first step to providing adequate care and support for all patients and their families. When there is a lack of social workers, they are likely to be utilized in situations for crisis management purposes. Although social workers are skilled in mediation and crisis intervention, their training in biopsychosocial assessment and early intervention are probably more beneficial for patients, families, the medical teams, and the hospital from the perspectives of patient satisfaction, treatment compliance, and cost saving by reducing expensive crisis intervention measures.

Another policy implication is for hospital administrators to encourage collaboration within the interdisciplinary team by clarifying each discipline's role and how members can support and compliment each other's expertise. While physicians and nurses manage the medical aspects of patients' disease course, social workers can focus on the emotional aspects of patients' cancer experiences. In addition, social workers' early involvement helps prevent miscommunication and ensure true communication between patients, families, and the medical team.

In terms of hospice under-utilization, changing the language and exploring comfort care as a form of treatment rather than "absence of treatment" may be the first step to promote a wider acceptance of hospice services. In addition, promoting education and awareness about palliative and hospice services to the general public may encourage patients to be more proactive in exploring such treatment options with their medical providers.

Recommendations for Future Research

Ideas for future research include performing the same study with a larger and ethnically heterogeneous group of social workers to increase external validity and generalizability. In this study, a sub-group of three hematology and bone marrow transplant social workers reported having 100% coverage of their patients and they reported being involved with patients' care from day one. I have not confirmed whether 100% social work coverage is a common practice among certain disease units or whether such coverage varies from hospital to hospital. One suggestion is to have separate studies to examine social workers' involvement and experience working with different cancer types. Finally, it would be interesting to have an in-depth examination of the

characteristics and psychological process of those who come to the decision to undergo the lengthy and intensive treatment of bone marrow transplant. Such information may shed light on how patients' characteristics and circumstances may have shaped the level of social workers' involvement with their patients during the end-of-life phase.

Conclusion

Cancer patients endure difficult physical and psychological challenges. People arrive at their end-of-life care decisions for different reasons. In addition to having accurate prognostic information, patients' wishes, values, beliefs, and biopsychosocial realities also have a strong influence on patients' end-of-life care decisions. This study highlights the importance of early social work involvement with cancer patients to provide guidance, support, and address various emotional aspects of their cancer experience. This study also notes that each cancer type follows different disease and treatment courses that may influence when and how end-of-life discussions come up. Although most patients seem to have an overall cognitive understanding of their medical condition, the emotional integration and implications of this understanding might take time for patients to come to terms with. Social workers' ability to facilitate communication among patients, families, and the medical team, makes them a crucial part of the interdisciplinary treatment team. Social workers' consistent support and the on-going discussions with their patients promote understanding and readiness as patients' experiences and understanding evolves.

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Appendix A

Human Subjects Review Approval Letter

December 23, 2008

Amy Kwan

Dear Amy,

Your second set of revisions has been reviewed and they are fine. You have resolved the thorny problem about recruitment. We are now happy to give final approval to your study with the understanding that you will add to the Consent the sentence about contacting the HSR Chair at the School at (413) 585-7974 should they have a concern or question. Check your second revision letter regarding this. Please send Laurie Wyman a copy of the Consent after you have added this for your file. This information for the participants is required by the feds.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Efrosini Kokaliari, Research Advisor

Appendix B

Informed Consent Letter

Date _____

Dear (Name of Participant),

Code # _____

My name is Amy Kwan, and I am a graduate student at Smith College School for Social Work. I am conducting a study to explore the effects of oncology social workers' involvement with cancer patients and their families on their decisions about end-of-life care. The data collected from this study will be used for my master's thesis and possible future publication.

As a participant, you will take part in a one-hour interview meeting with me in a quiet, public place upon which we mutually decide such as the library or your office. First, you will sign this informed consent letter. Next, you will fill out a basic demographic questionnaire that should require no more than 5 minutes to complete. Then, I will ask you a list of guided interview questions that attempt to capture the experience you have working with cancer patients and the level of discussion you have with them specifically on the topics health status, and death and dying. I will audio-record the interview and take notes as we talk.

We understand individual social workers have different perspectives, unique working styles, and are faced with restrictions and limitations within various system settings. Questions in this study are expected to elicit a reflective process but they are not intended to critique your experience or behaviors. Please note that you may discontinue participation in the study at any point, without penalty. If you have any concerns about this study, you may speak with me, or you may contact the Chair of the Human Subject Review Committee, at the Smith College School for Social Work at 413-585-7974.

The findings of this study will reveal no identification of specific individuals. Data will be aggregated and all information about individuals will be held in confidence. However, as your name could have been provided to me through a colleague or professional acquaintance of yours, there is a possibility that others might know of your participation in this study. Furthermore, as we may conduct interviews at your place of employment, other staff may observe that you are engaging in an interview with me. I will protect and maintain confidentiality of what you share with me in your interview. As I will use a numerical code to identity your data, your name and the name of your agency will not appear on the transcripts, my thesis, its dissemination, or possible future publication.

I will be the only person who has access to the audio-recording and your interview transcript in its entirety. My thesis advisor will have access to the transcript after all identifying data has been removed. In my thesis and any other presentation of the data,

all quotes and illustrative vignettes will be written in a manner that does not reveal information that could identify you, your patients, or any actual characters. According to federal guidelines, I will keep all of the notes, transcripts, audio-recording, and this informed consent letter in a securely locked location for three years. The identifying information on this letter will remain separate from your interview data. Beyond this three year period, data that I am not actively using will be physically destroyed by me.

A potential benefit for your participation in this study may include an opportunity for you to reflect on and to share your rich experiences of working with cancer patients and their families. You may gain deeper insight into these experiences and be able to incorporate these insights into your future clinical practice. In addition, participation in this study will offer you the opportunity to contribute your valuable perspective to the overall body of knowledge on how to better serve individuals with serious and life-limiting illnesses. You will, however, receive no monetary or other material compensation for your participation in this study.

Your participation in this study is voluntary. You may withdraw from the study at any time up until April 1, 2009, at which point my report will be turned in for review. If you wish to withdraw, either before, during, or after the interview, you may either notify me in person or contact me by writing, email, or phone via information provided below. All materials relating to you will be immediately destroyed by me. You will not be penalized in any way if you decide to withdraw from the study.

Your signature indicates that you have read and understood the above information and you agree to participate in this study.

Participant's Signature	Date	Investigator's Signature	Date
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Please contact me at anytime if you have any questions about this study. Thank you very much for your participation in this study and for your generosity of time and energy.

Sincerely,

Amy Kwan, MSW Candidate
Beth Israel Deaconess Medical Center
330 Brookline Avenue
Boston, MA 02215
Phone: 617-667-3990
Email: akwan@smth.edu

Appendix C

Demographic Questionnaire

Please provide the following information as part of the study

1. Code #: _____
2. Age: _____
3. Gender: _____
4. Racial and/or Ethnic Identity: _____
5. Number of years working as a clinical social worker with a MSW degree: _____
6. Number of years working in the field of medical social work: _____
7. Number of years working as an oncology social worker in the current hospital: _____
- 7a. Name of the unit: _____

Appendix D

Guided Interview Questions

The following questions will provide a guide for the interview process. They indicate general areas of inquiry in which this study intend to explore

Introduction

“I would like to ask you some questions about your experiences working with cancer patients who are receiving active treatment in a hospital setting. I am interested learn about the *types and extent of involvement* and *topics of conversation* that you have with these patients and their families. I also want to understand from your experience, how your level of involvement in patient’s care affects their end-of-life care decisions. Feel free to ask for clarification during the interview at any point. Interview questions are broken down into three sections.”

I. Types and extent of contact:

“Section I. I will first ask you questions about the overall process of your engagement with a patient.”

1a. Could you please tell me, when a cancer patient is receiving active treatment here, who is involved in his/her care? (Prompt: Who are included in the treatment team and who do the patients meet with?)

Who do you work with in the interdisciplinary team?

1b. Please describe the way referrals are being initiated. For example, under what circumstances are patients being referred?

Do you think there’s a relationship between the stages of disease and the time of referral?

1c. How do you introduce your role to patients and families?

1d. Could you give me an average or an estimated number of sessions you’ll have with a patient?

1e. How often and under what circumstance are families involved in these meetings?

1h. Do social workers get assigned or at least be notified about returning patients?

II. Discussion about diagnosis, prognosis, treatment options, and implication on quality of life

“Section II. I will now about the types of communication you have with your patients and their families about their health conditions.”

2a. How involved are you in the discussion about patient’s understanding of their diagnosis, prognosis, treatment options, and their implications on quality of life?

2b. Do you feel there’s a need for a social worker to clarify this information with patients and their families?

2c. Do you think that most patients have a clear understanding about this information by hearing from the doctors and nurses? And what might contribute to this outcome?

2d. How does the treatment team react to your participation in helping to clarify this information with patients and their families?

2e. How do you think having this discussion affects patients’ end-of-life care decisions?

III. Discussion about death and dying

“Section III. I will ask you questions about the types of communication you have with your patients and their families about death and dying.”

3a. How often does the discussion of death and dying take place with your patients and their families? Usually, who and under what circumstance does this discussion gets initiated?

3b. How would you bring up the discussion about death and dying? Please provide examples.

3c. Does the topic get revisited if the patient or family initially declines to discuss it? If so, please explain how and under what circumstances.

3d. What are some barriers that you can identify of having this discussion?

3e. How do you think having this discussion affects patients’ ultimate end-of-life care decision?

* Additional Comments: Are there anything else you would like to add to the comments you have made so far?

* Last question: What are other factors that may prevent cancer patients from accessing hospice care in a timely manner?